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Title

What happens before, during and after crisis for someone with dementia living at home: a systematic review

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Abstract

Background

People living with dementia often experience crisis. Home treatment of crisis is an alternative to hospital admission that can have better outcomes. This systematic review is about people with dementia living at home and in crisis. It identifies modifiable factors in the crisis process that may facilitate crisis resolution.

Methods

The protocol is registered on PROSPERO. A systematic search of MEDLINE, EMBASE, CINAHL, AHMED, PsycINFO, Cochrane Library, and references of retrieved publications, identified empirical research in English language and date range 1/2000 to 2/2019. Two researchers independently screened abstracts, selected publications and extracted data using a framework based on published guidelines. This is a report of the analysis and narrative synthesis.

Results

The search identified 2,755 titles and abstracts, 76 were selected for full-text examination and 13 agreed for inclusion. The included studies evidence that:

For a person with dementia, crisis is a process that begins with a problem judged to put them or others at risk of harm. It leads to decision and action to treat this risk, thus resolve the crisis. Such crisis can be predicted or unpredicted and progress quickly or slowly.

Medical treatment, community resources, and psychosocial support of personal resources, decision making, relationships, and social networks, are all modifiable factors that can treat the risk of harm during crisis. Carers' and professionals' knowledge and skills in dementia care are likely to play a key role in crisis resolution in the home.

Conclusion

There has been limited investigation of the process and management of crisis at home for people living with dementia. The results of this review provide a foundation for future research. There is no consensus on critical components of home treatment to facilitate crisis resolution. However, education in dementia care for carers and professionals is likely to prove essential to successful home treatment.

Keywords

Dementia, crisis, community, systematic review

Introduction

Worldwide, crisis is a recognised problem for people with dementia living at home (Backhouse, 2018; Streater, Coleston-Shields, Yates, Stanyon, & Orrell, 2017). Community crisis services have been developed in many countries ((Johnson et al., 2013; Lloyd-Evans et al., 2018; Tibaldi et al., 2004)), and home treatment can achieve crisis resolution in people with dementia (Toot, Devine, & Orrell, 2011). Best practice guidance in dementia care is for support in the home whenever possible (Fazio, Pace, Maslow, Zimmerman, & Kallmyer, 2018; GAC, 2016; NICE, 2018), because of the known adverse outcomes of hospital and institutional care for people with dementia (NICE, 2018). Developing effective community crisis services is important for delivery on the global dementia action plan(WHO, 2018) , which proposes that shifting care from hospital to multidisciplinary, community based settings will help to achieve its objectives. To develop successful crisis resolution services in the community we need to know what happens before, during and after a crisis to decide what to do to prevent crisis, facilitate rapid resolution and sustain resolution.

Scoping review

We conducted a scoping review (LY, JH) (unpublished, available from first author) to inform our systematic review question, to decide the time period and clinical practice boundaries of our review, and to find out if similar reviews had previously been published. We found investigation of both causes of crisis (Ledgerd et al., 2016; Toot, Hoe, et al., 2013) and crisis prevention in people with dementia (Fortinsky et al., 2016; Goeman, Renehan, & Koch, 2016) with crisis defined as a process where a stressor causes an imbalance requiring a decision for resolution (MacNeil Vroomen, Bosmans, van Hout, & de Rooij, 2013). We also found no common understanding of home treatment for people with dementia in crisis and a lack of clarity around its essential component parts. What we learned informed our published systematic review protocol (Hopkinson et al. 2018) and enabled us to devise a search strategy in consultation with a librarian.

The purpose of our subsequent systematic search of empirical research was to explore what is known about people with dementia living at home and in crisis. It aimed to reveal factors that might be

important for crisis resolution through a synthesis of quantitative and qualitative data on crisis experienced by people with dementia, their carers and professionals involved in their treatment and care.

Review Question

What is known about the causes, manifestations (presentation), management and outcomes of crisis for people with dementia living at home?

Objectives

- To describe dementia crisis from cause, presentation and management through to outcomes.
- To identify potentially modifiable factors for i) improving the experience of people with dementia and their carers during crisis and ii) resolving crisis.

Design and methods

The protocol is registered with PROSPERO (Moher, Liberati, Tetzlaff, & Altman, 2009). The search methodology and methods were informed by the NHS Centre for Reviews and Dissemination guidance for undertaking reviews in healthcare (Centre for Reviews and Dissemination, 2009) and the review is reported in compliance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidance (Liberati et al., 2009).

Search strategy for identifying data sources

Relevant empirical studies were identified by conducting a search of electronic databases: MEDLINE, EMBASE, CINAHL, AHMED, PsycINFO, The Cochrane Library (Cochrane Database of Systematic Reviews, and the Cochrane Central Register of Controlled Trials (CENTRAL). Limits

were English Language and date range January 2000 to February 2019. The search was iterative, with reference lists of all full text publications screened to identify further relevant titles.

The search was developed on Ovid MEDLINE using the keywords and MeSH headings (see Appendix I) and then adapted for use with other biographic databases. The search terms were the concepts 'crisis,' 'home,' 'dementia,' ' and their equivalent concepts combined using 'AND.'

Eligibility criteria

The scoping review and discussion with a home treatment crisis resolution team identified the following eligibility criteria

Inclusion

- Diagnosis of dementia (any type)
- Crisis (or equivalent terms used by study authors)
- Living at home (private dwelling)
- Any perspective (patient, informal carer, paid carer, healthcare professional, service provider)
- Studies of single interventions or forming part of a multi-component intervention (Crisis intervention/crisis management/crisis resolution/ home treatment)
- Primary research using any methodology or method (i.e. data is collected and analysed)
- Adults over the age of 18 (no upper age limit)
- English language publications only
- Year of publication 2000-2/2019

Exclusion

- Mental health crisis in absence of dementia e.g. psychosis
- Opinion/letters/audit/protocols/conference abstracts/book/ single clinical case studies/ reports/thesis/dissertation/reviews/systematic reviews

- Crisis treated in hospital/crisis treated in an emergency department
- Remodelling/restructuring of services e.g. change in commissioning
- Community hospital, hospital, care home, nursing home
- End of life/terminal care
- Children and adolescents

Data extraction and management

Two review team members screened each identified title and abstract independently for eligibility (JH and KH, JH and LY, JH and SK, JH and SM, JH and JM, JH and MK). Further examination of the full text followed if either reviewer judged the abstract eligible. Two members of the review team read each of the full text papers (JH and KH, JH and LY, JH and FE, JH and MK, or JH and JM). The papers were screened for eligibility and data extracted if the paper met criteria for inclusion. Data extracted included; publication focus, study methodology, study location, people involved in crisis management, cause of crisis, manifestation of crisis, management of crisis, and outcome of crisis. The screening tool and data extraction sheet was devised based on published guidelines and the Cochrane Evaluation of Practice and Care Group's template (Moher et al., 2009) (see Table 1.). Where there was disagreement between reviewers, a third reviewer was engaged in the decision making process. Included papers were quality assessed using the Effective Public Health Practice Project Quality Assessment Tool for Quantitative Studies (EPHPP, 2009) or the Critical Appraisal Skills Programme checklist (CASP, 2018) for qualitative research.

Data analysis and synthesis

We anticipated heterogeneity in study design, methodology and methods following our scoping review and thus did not plan a meta-analysis. The analytic plan was to extract relevant data and then conduct an exploratory qualitative analysis and interpretation. Two researchers, working independently, extracted and categorised information from the findings and discussion of included papers (JH and KH, JH and LY, JH and FE, JH and MK, or JH and JM) using the data extraction

form as a framework. Inconsistencies in data extraction were identified (JH) and revised following agreement by the two reviewers. The data was then tabulated using the three components of our research question as a framework (JH) (see Table 2. and Table 3.):

- Cause of crisis,
- Manifestation (presentation) of crisis and its management (interventions and their mechanisms of action) and
- Crisis resolution or solution.

The method of cross-case analysis was used to compare and contrast findings across studies included in the framework (Miles M, 1994) for each of the three assumed components of a crisis process; before, during and after (JH). It provided a foundation for narrative synthesis of empirical findings addressing the research questions about crisis for people with dementia living at home (Britten et al., 2002; Pope & Mays, 2006). The synthesis adopted a mapping and modelling method (Miles and Huberman, 1994) to identify relationships between concepts in the crisis process leading to the generation of a model of dementia crisis (JH). This model was checked for disconfirming evidence and refined (JH)(van Manen, 1990). It was then checked for credibility with the authors who include mental health (SM, SK, KH) and dementia care clinicians (LY, MK, SM, KH) and teachers (MK, JM).

Results

Thirteen studies about crisis for people with dementia living in their own home have been included in this review.

The search in MEDLINE, Embase, PsycINFO, Ahmed, CINAHL and the Cochrane Library from January 2000 to May 2018 and updated on 4th March 2019, identified 2,728 titles and abstracts. A search of the reference lists of included full text publications found an additional 27, thus yielding a total of 2,755. Two reviewers read the seventy-two full-text publications selected from the initial

search and four identified through the backward chaining process (total 76). Thirteen met the criteria for inclusion (see Figure 1.).

The included studies were conducted in USA (n=5), Canada (n=1), UK (n=3), Australia (n=2), Netherlands (n=1), and Ireland (n=1) (see Table 2), ten published within the past decade. One study was a quasi-experimental pilot study designed to compare two approaches to crisis management in people with dementia, but with reported analysis about change in the group managed in the community, thus being a quantitative study of weak design. Three studies were surveys, with analysis of one complemented by interview data and one complemented by routinely collected clinical data. All were of weak design. The remaining nine studies were qualitative explorations, eight with interview data collected from people with dementia and/or informal carers and/or professionals. One of the eight also used workshops to collect data, whilst the ninth drew on data from focus groups. Two of the studies were of strong quality, the other seven being of fair or limited quality, primarily because of a lack of either consideration of the transferability of findings or of researcher influence. Studies were included irrespective of quality because of the limited number identified and the decision to conduct an analysis where the findings of the studies were the data for a qualitative interpretive synthesis. Whilst based on all literature found by a systematic search, there may be selective reporting in the poorer quality studies and thus our analysis may include some atypical experiences of crisis in the home for people with dementia. Hence, the analytic product probably encompasses outliers, in addition to the most commonly experienced crises.

A total 2,077 people took part in the studies. Participant numbers ranged from 15 to 806 (median 40). One hundred and fourteen people with dementia took part in five studies with numbers ranging from four to 77 (median 11). All studies collected data from carers, with five recruiting from this subgroup only. The combined total of carer participants was 1,255 their subgroups numbering from from 15 to 806 (median 20). Data was collected from a combined total 724 professional across seven studies with subgroup numbers ranging from 15 to 611 (median 19).

The small size of study sample populations, the exploratory nature of the empirical studies, and the discovery of only six studies where the primary purpose was to investigate crisis for people living with dementia, demonstrates limited investigation of the crisis process and its management in the homes of people with dementia.

What is crisis?

There is no shared and consistently used understanding of crisis for people with dementia living at home. One of the included studies provided no definition or description of crisis (Galvin et al., 2010), as the primary purpose was not to investigate crisis. Six papers gave examples of crisis. These were a missing person incident (Bowen, McKenzie, Steis, & Rowe, 2011), illegal/dangerous driving (Liddle et al., 2013), an emergency in the home, such as a fall (Meiland et al., 2014), a carer being unable to manage a situation and/or continue providing care (Bruce, 2002; Donnelly, 2017; Jacobsohn et al., 2019). Six papers provided a definition of crisis used (see Table 3.). Two papers (Ledgerd et al., 2016; Toot, Hoe, et al., 2013) used MacNeil Vroomen's (2013) literature derived definition of crisis (MacNeil Vroomen et al., 2013). This definition has a psychological focus with crisis understood as a process where stressors increase to the point of exceeding coping resources and resolution achieved when homeostasis is re-established. The focus of three other definitions was a change in medical condition placing the person with dementia at risk of harm; psychiatric symptoms (Johnson et al., 2013), cognitive decline (Strang, 2006), or exacerbation of an existing chronic condition or new acute illness (Sadak, Foster Zdon, Ishado, Zaslavsky, & Borson, 2017). Liken's paper focuses on crisis as being a failure of individual problem solving process, but within a social system that works to maintain homeostasis (Liken, 2001). Thus intrapersonal (e.g. knowledge), interpersonal (e.g. relationships) and extrapersonal (e.g. available community services) factors are all assumed to influence the crisis outcome, whether that be positive or negative.

What is common to all definitions and examples of crisis reported is an understanding of crisis as risk of harm to either the person with dementia or another person. Another finding common to the studies is that crisis commences with a problem (or change) that increases this risk, prompting a

process of problem recognition and management through to resolution. The studies differ because they focus on different causes of risk. This influences the different approaches to problem management and resolution they identify. When the cause is a medical condition, then resolution is through treatment. When the cause is stress, then resolution is to reduce stress and support adaptation. When cause lies within the psychosocial context, then resolution is to strengthen personal resources, relational and social care networks. Jacobsohn et al. (2019) allude to multiple causation when they propose that emergency department staff with their focus on medical treatment may miss and/or be unable to address crisis of psychosocial origin (Jacobsohn et al., 2019).

What happens before crisis?

Toot et al (2013) and Legerd et al (2016) are members of the same research team working on a programme of research seeking to improve care of people with dementia living in the community. Their papers report both survey and focus group work to establish causes of crisis. There is much overlap in findings, which are categorised as, behavioural and psychological factors, physical health problems, vulnerability (e.g. lack of insight), family carer factors and environmental factors. The causes identified by other research reported in this review are not as comprehensive in scope but do fall into one or more of these categories. However, they draw on additional data sources that reveal characteristics of the pre-crisis process not evident in the analysis conducted by Toot et al. (2013) and Ledgerd et al. (2016).

Crisis may be unpredicted or predicted (Liken, 2001). A crisis may present with no warning and no apparent cause. Cited examples include an acute physical health problem, such as hip fracture (Sadak et al., 2017), neuropsychiatric symptoms, such as agitation (Johnson et al., 2013), and the person with dementia going missing when left in a situation they had previously managed on their own (Bowen et al., 2011). Alternatively, a crisis can be predictable, following a chain of risky situations prompting interpersonal conflict. An example is driving incidents that prompt conflict with family members about whether the person with dementia should continue to drive (Liddle et al., 2013). Another example of multiple pre-crisis events is failure of communication across services

resulting in errors and leading to an acute medical situation (Jacobsohn et al., 2019). The behaviour of carers plays an important role in the presentation of a crisis (Liken, 2001). Crisis can happen because carers are reluctant to seek help. They may deny the dementia diagnosis or related problems, have a strong sense of duty to care and believe they should cope without help (Bruce, 2002). They may also be concerned about wasting scarce professional resources or think general practitioners (GPs) are too busy to consider non-medical matters or lack dementia care skills (Bruce, 2002; Jacobsohn et al., 2019). The person with dementia may also be unwilling to accept community support (Bruce, 2002). Johnson et al.'s (2013) study found 73% of carers, prior to education, believed nothing can be done to help with the management of neuropsychiatric symptoms for the prevention of crisis (Johnson et al., 2013). Some crises that present as unpredicted problems requiring urgent action might be prevented through earlier intervention.

What happens during crisis

During a crisis, the risk of harm is considered alongside adverse consequences of possible interventions. There is thus an assessment of how action to reduce risk should be balanced against it consequences, such as restriction on freedoms. The studies that report particular examples of crisis management illustrate this well. Liddle et al. (2013) describe driving related incidents that include near misses, collisions with vehicles or pedestrians, getting lost and unlicensed driving to evidence safety issues with driving for people with dementia (Liddle et al., 2013). They identify the losses for the person with dementia if they stop driving, such as increased isolation, which make for a difficult discussion within families with pressure to cease driving resisted by the person with dementia. In one case, a father became physically aggressive towards his daughter when she took his car key. Strang et al. (2006), Meiland et al. (2014), and Liken et al. (2001) describe similar examples of safety issues resulting in carers deciding to take action because the situation had reached crisis point (Liken, 2001; Meiland et al., 2014; Strang, 2006). Reported examples of taking action to prevent harm included seeking professional advice, accessing services, and restricting or monitoring activity of the person with dementia.

As with the cause of crisis, the need for crisis management may be either unpredicted, or predicted due to a history of problems leading up to a decision to take action (Liken, 2001). Action might be taken because of a sudden and unexpected change, such as the carer breaking an arm (Sadak et al., 2017) or the person with dementia going missing (Bowen et al., 2011). Conversely, it can follow a period of uncertainty about what to do for the best (Jacobsohn et al., 2019), such as during a period of time when the person with dementia has become lethargic or a period where the carer becomes deprived of sleep whilst monitoring the person with dementia (Sadak et al., 2017). Once the decision to take action to resolve the crisis is made, there may be an immediate intervention, for example, admission to hospital (Sadak et al., 2017), or a time of waiting, for example, whilst on a waiting list for a long term care placement (Strang, 2006). The decision to seek help from an emergency department to resolve a crisis is common. It was a course of action reported by 64% (506) of carers of people with Lewy Body Dementia in USA who completed a survey, with subsequent in-patient psychiatric care given in more than 1 in 10 (Galvin et al., 2010). Help may be sought from an emergency department because people involved in the crisis do not know about alternative options (Jacobsohn et al., 2019).

There are often many people involved during a crisis. They can include; carer, family, friend, community members (Bowen et al., 2011; Ledgerd et al., 2016; Liken, 2001; Toot, Hoe, et al., 2013), general practitioner (Bruce, 2002), medical services, law enforcement agencies (Galvin et al., 2010; Ledgerd et al., 2016; Toot, Hoe, et al., 2013), specialist crisis intervention teams, and support workers for people with dementia or unpaid/paid carers (Bruce, 2002; Johnson et al., 2013; Ledgerd et al., 2016; Meiland et al., 2014; Toot, Hoe, et al., 2013). The factors that influence decision making and action include the availability of; hospital, respite, specialist and community services (Donnelly, 2017; Ledgerd et al., 2016; Toot, Hoe, et al., 2013), equipment and technology (Ledgerd et al., 2016; Toot, Hoe, et al., 2013), flexible and easily accessible services (Ledgerd et al., 2016; Toot, Hoe, et al., 2013), carer support services (Ledgerd et al., 2016; Toot, Hoe, et al., 2013) and carer knowledge and skill (Bruce, 2002; Sadak et al., 2017).

The studies reveal that crisis management involves decision and action to reduce risk of harm, which takes into consideration not only the availability and benefit of interventions but also their negative consequences. Crisis management can progress quickly or slowly and can involve the person with dementia, carers, paid carers, family, community, general practitioner, medical services, community health and care services, emergency services and law enforcement. Knowledge of available management options is important to decision making and thus the course of crisis .

What happens after crisis?

The person with dementia may be unaware of crisis occurrence, for example, by forgetting having been lost (Bowen et al., 2011) or forgetting recent driving incidents (Liddle et al., 2013). This can be a source of on-going conflict with family members (Liddle et al., 2013). Carers and family members can reflect that the crisis could have been avoided with education and support pre-crisis (Jacobsohn et al., 2019) or whilst the person with dementia was better able to learn new skills (Liddle et al., 2013). Carers can wish they had sought help sooner (Bruce, 2002) and think this may have prevented the need for respite or hospitalisation (Bruce, 2002). Carers' belief that future similar crises were predictable and preventable influenced their decision to take or plan further action, such as modify the home environment (Bowen et al., 2011).

Hospital admission can become the default risk management option if there are insufficient community services to support dementia care at home, such as during a period when a carer is unwell, thus leading to further declines in condition and subsequent long term care placement (Donnelly, 2017). A specialist Dementia Crisis Care Coordinator focused on the management of neuropsychiatric symptoms in the home can reduce symptoms and negative impact on carers, significantly reducing their related distress and increasing confidence in the management of difficult behaviours (Johnson et al., 2013). In 24 people with dementia at risk of nursing home placement (53%) placement was delayed (Johnson et al., 2013). However, interventions that reduce risk can contribute to a sense of loss of identity and increasing isolation (Liddle et al., 2013). Carers who are failing to cope, can view care home placement as a good way to resolve the crisis (Liken, 2001).

However, they are likely to want to continue involvement in care if they have a caring relationship with and emotional commitment to the person with dementia (Strang, 2006). Carer beliefs, knowledge and relationship with the person who has dementia influence what happens post crisis.

A model of crisis for people with dementia living at home

The study findings included in this review enable the construction of a model of crisis for people living with dementia at home. Crisis is a process that begins with either an unpredicted problem, such as an accident, or a predicted problem because of preceding similar events. The problem disrupts everyday life to a level where risk of harm to the person with dementia or others is identified, leading to a decision to take action either within the home or within a hospital environment. The process of disruption leading to assessment of risk of harm may happen quickly, for example when a carer becomes unwell. In other circumstances the same process may be prolonged, for example, as the risk caused by fluctuating driving ability becomes recognised. Chosen action depends on how the problems is understood, it might be understood as being a medical problem needing treatment, emotional stress needing support for adaptation, or a psychosocial problem needing support to strengthen personal resources, relational bonds or social networks. Deciding what to do and acting on the risk may happen quickly, for example, when the person with dementia is threatening suicide, or become prolonged, such as when there is a wait for a care home placement. Resolution to the crisis may be achieved through risk reduction in the home or risk reduction through admission to hospital or a long term care facility. Crisis management thus comprises risk identification, risk assessment and the implementation of a decision to act to reduce risk of harm i.e. a risk management process. Post resolution, adjusted life with dementia may or may not continue with on-going proactive support to reduce risk of future crisis.

[Insert Figure 2: model of the crisis process for people with dementia living at home]

This model supports the following propositions:

Attitudes and beliefs influence the course of crisis. Belief that supportive intervention can reduce the risk of future crisis influencing pre-crisis and post-crisis behaviours.

Decision making and action to resolve crisis will depend on perceptions of risk of harm.

Assessment of risk of harm and resources available to treat risk are central to crisis management in the community.

Some crises seem to present with no warning but may be preventable with pre-crisis education and support.

Therefore, the findings of this review support the proposition of factors that may result in more people with dementia supported through crisis at home:

Attention to education of carers, professionals and the wider community in the potential benefits of supportive and preventive intervention to reduce the risk and incidence of crisis (raising awareness of the green course through crisis in Figure 2.).

Attention to the process of identifying and assessing risk of harm, which may involve the use of assistive technology, and decision aids.

Availability of resources in the community for proactive post crisis support in the home.

These are propositions that can be tested for effect on crisis management in future research.

Discussion

This review found no consistent definition of crisis for people with dementia living at home amongst the included studies. However, the analysis reveals a common basis for understanding, which is that a crisis for someone with dementia is:

a process that begins with a problem judged to put a person with dementia or others at risk of harm. It leads to decision and action to reduce this risk thus resolving the crisis. It can be predicted or unpredicted and progress quickly or slowly.

The analysis also showed that:

medical treatment, community resources, and psychosocial support of personal resources, decision making, relationships, and social networks are all modifiable factors that can be used to treat the risk of harm during crisis.

This understanding is consistent with definitions of crisis resolution services to '…reduce likelihood of death, harm to themselves or someone else…' (TAC, 2005). It differs from definitions used in the studies reviewed (Johnson et al., 2013; Liken, 2001; MacNeil Vroomen et al., 2013; Sadak et al., 2017; Strang, 2006) in two important ways by drawing attention to the temporal variability of crisis and the importance of its relational and social context.

The analysis also revealed what is known about crisis from cause and presentation, through management, to outcome for someone with dementia living at home.

Before crisis: There may be no awareness or acknowledgement of the potential for crisis

The review identified crises as having different causes. These are an acute medical condition, dementia progression, emotional stress in patients and/or carers, neuropsychiatric symptoms, psychosocial context, or combinations of these factors. The review also found professional and carer knowledge, skill and beliefs to be important for early risk of harm recognition and knowing

what can be done. Studies investigating the reasons for hospitalisation in people with dementia similarly report both carer and healthcare professional beliefs about the potential for prevention of unplanned hospital admissions influence pre-crisis intervention (Pohontsch, Scherer, & Eisele, 2017).

Bowen et al. (2011)'s study collected data from carers and evidenced people with dementia may have no recollection of a past crisis, as their carers reported 'that they did not realise that they were missing.' This could explain why retrospective carer accounts of events and behaviours leading into crisis form the primary source of information about crisis causation. This is problematic because some groups of carers are less likely to use community services, including those who are older and depressed (Robinson, Buckwalter, & Reed, 2013), and could thus lack the education and support in dementia care that would help them identify changes that cause crisis. Communication skill training for dementia carers can reduce their anxiety, depression and burden (Morris, Horne, McEvoy, & Williamson, 2018). Psychoeducation can also alleviate depression and burden in dementia carers (Laver, Milte, Dyer, & Crotty, 2017; Vandepitte et al., 2016). There may be important actionable factors for earlier recognition of crisis risk, not yet reported in the literature.

During crisis: Optimal risk management may require a broad multi-causal look at crisis in the home

We found that there is a decision to be made during any crisis, which requires an assessment of both benefit and loss for any course of action. Wackerbarth (1999) presents a model of the decision making process for carers of a person with dementia in crisis (Wackerbarth, 1999) . Based on case study approach and multiple methods of data collection, the argument is made for carers being in a dynamic situation where they are making judgments about how best to manage the tension between respecting the freedoms of the person with dementia whilst reducing the risk of harm to a tolerable level. We have found these decision(s) may involve many people who need to consider multifaceted causation and know the options for crisis resolution. There is potential for benefit from decision support.

Although the review found multiple categories of crisis causation, eleven of the included studies focus a specific cause. In five studies, the focus was the informal carer's ability to continue in their role. In three others, the focus was neuropsychiatric symptoms and in three studies, the focus was an acute medical condition. Thus, physical and mental health and carer issues have typically been studied in isolation. This pattern repeats with systematic and scoping reviews focusing on behavioural crisis (Backhouse, 2018; Jennings et al., 2018) and mental health crisis (Streater et al., 2017; Toot et al., 2011) or the psychosocial system supporting coping and adaptation (Parker, 2007). Yet the defining characteristics of dementia, memory and attention deficit are often accompanied by behavioural (repetitive) and affective symptoms (low mood) which can cause physical health problems, such as failure to complete self-care tasks to manage comorbid conditions. Neuropsychiatric symptoms become more likely as the disease progresses (anxiety, depression, psychosis), as also do physical health problems. The relationship between physical and mental health problems and the wider relational and social context of crisis for people with dementia seems to have received little attention in the literature, despite being potentially modifiable for crisis resolution.

During crisis, current practice may fail to consider the full range of biopsychosocial interventions. The broader literature demonstrates that emergency departments may ignore underlying psychosocial factors contributing to a physical health crisis (Onen et al., 2001), appropriate services are not always be available to offer biopsychosocial support in the community (Jennings et al., 2018; Pohontsch et al., 2017; Purdy, 2010) and primary care staff may not know what services are available (Jennings et al., 2018). Furthermore, when fewer community resources are available, the demand on emergency department increases, particularly in those with cognitive impairment (D'Souza, James, Szafara, & Fries, 2009). This eventuality is undesirable given the evidence that home treatment for someone with dementia can have better outcomes than treatment in hospital. For example, a study that randomised people with dementia presenting with an acute illness in an emergency department found equivalent medical outcomes but less behavioural disturbance and lower care stress in those managed by a geriatric hospital at home service compared to those admitted to hospital (Tibaldi et al., 2004). This review supports Toot et al's (2013) proposition that

for a reduction in acute hospital admissions in people with dementia requires ‘a more holistic approach to providing community dementia care, encompassing the cognitive, behavioural, psychological and physical needs of people with dementia and providing responsive care packages and health education to both people with dementia and their carers’ (Toot, Devine, Akporobaro, & Orrell, 2013).

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After crisis: It may be possible to prevent future crisis episodes for people with dementia

The review found that some people with dementia, their carers and healthcare professionals believe early intervention can prevent a crisis arising. In the study by Johnson et al. (2013), a majority of carers changed their view after exposure to education and support, coming to believe prevention of crisis possible. It may well be possible to predict risk of harm and intervene early in certain cases. Assessment tools may also help. Tierney et al. (2007) found deficits in retrieval and storage of information, visual scanning and motor speed, and verbal conceptualisation or abstract reasoning, to predict risk of harm, such as failure to use medications properly (Tierney, Snow, Charles, Moineddin, & Kiss, 2007). Furthermore, carers taught to recognise new and worsening symptoms may be able to identify risk of harm earlier (Sloane et al., 2017). Carers randomised to receive psychoeducation via a telephone helpline increased their use of community services and reduced their use of emergency departments compared to a control group (Tremont et al., 2017). Crisis may be ‘a time of opportunity and therapeutic potential’ (Parker, 2007) where education and assessment tools can influence decision and action to prevent future crises.

We need to know more about the process of crisis management and outcomes

This review demonstrates education and support of carers to be important for management of risk for crisis prevention and crisis resolution in the home. It also found availability and awareness of community services, such as day care and respite services to be important for the offer of a biopsychosocial multicomponent home treatment of risk for people with dementia in crisis. The outcome of home treatment given most attention is admission to hospital and long term care

placement, or prevention of these outcomes. There may be other benefits for both people with dementia and their carers. These include improvement in quality of life or avoidance of hospital prior to long term care placement. We now need high quality empirical research to evaluateessential components of complex intervention for successful home treatment, to understand the full range of benefits, and to identify sub-groups of people with dementia for whom home treatment is an effective and preferred alternative to hospital.

Limitations

This review considered only English language publications about crisis for people with dementia living at home and published from January 2000 to February 2019. A small number of studies met the inclusion criteria and all were exploratory. Carers of people with dementia provided the majority of data, thus carer perspective is overrepresented in the analysis compared to people with dementia, professionals or other stakeholders. Similarly, we do not know if the people with dementia represent the population living in their own homes, as our analysis did not consider how dementia stage might influence the crisis process, as only three studies reported this information for participants. It proved challenging to identify publications about crisis for people with dementia in the home, because of the lack of a consensus definition and inconsistent use of the term crisis across studies. Some studies about crisis may be missing where alternative terminology is used. Furthermore, there was no search of grey literature. There are other literatures relevant to understanding crisis for people with dementia but beyond the scope of this review. These are literature about prevention of crisis, the management of crisis in hospital and the management of crisis in the emergency department.

Conclusion

There is little empirical research investigating the process of crisis for people with dementia living at home. Policy emphasis in the western world is on care in the community and crisis intervention in the home, because of the potential for better health and wellbeing outcomes compared to hospital

care. This review has devised an empirically based definition and a biopsychosocial model of crisis in people with dementia living at home. It provides a foundation for future research and evaluation of home treatment in crisis for people with dementia.

Ethical approval

No ethical approval was required for the reported analysis of data sources.

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Conflicts of interest

The Authors declare that there is no conflict of interest.

Supplementary material

Available from the first author.

Appendix 1: Search strategy: MEDLINE (OVID)

Database: Ovid MEDLINE(R) <1946 to March Week 3 2019>
Search Strategy:
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1 community.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (443430)
2 primary care.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (91362)
3 exp Primary Health Care/ (144554)
4 Home Care Agencies/ (1317)
5 Home Care Services/ (32004)
6 Home Health Nursing/ (266)
7 Home.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (201024)
8 Home Nursing/ (8427)
9 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 (767796)
10 exp DEMENTIA/ or FRONTOTEMPORAL DEMENTIA/ or DEMENTIA, VASCULAR/ or DEMENTIA, MULTI-INFARCT/ (152354)
11 dementia.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (99375)
12 exp Alzheimer Disease/ (86248)
13 alzheimers.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (98479)
14 exp Memory Disorders/ (27932)
15 memory loss.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (3237)
16 LEWY BODY DISEASE/ or LEWY BODIES/ (4239)
17 exp DELIRIUM/ (8372)
18 FRONTOTEMPORAL LOBAR DEGENERATION/ (1040)
19 Cognitive Dysfunction/ or Cognition Disorders/ (72820)
20 cognitiv* impair*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (47411)
21 cognitiv* impair*.mp. [mp=title, abstract, original title, name of substance word, subject

heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (47411)
22 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 (289749)
23 emergency.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (246930)
24 Emergencies/ (38915)
25 crisis*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (45435)
26 exp Crisis Intervention/ (5541)
27 23 or 24 or 25 or 26 (305519)
28 9 and 22 and 27 (568)
29 limit 28 to (english language and yr="2000 -Current") (432)

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